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Promoting wellbeing and resilience

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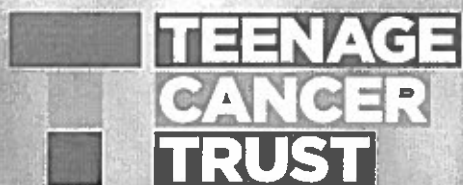
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THE BLUEPRINT OF CARE

for teenagers and young
adults with cancer

Second edition





The **BLUEPRINT OF CARE**
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CHAPTER SEVEN: PROMOTING WELL-BEING AND RESILIENCE

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THE IMPORTANCE OF WELL-BEING AND RESILIENCE FOR YOUNG PEOPLE WITH CANCER

TYA VULNERABILITY

Young people with cancer are recognised 'as a small but in many ways a uniquely vulnerable group of cancer patients'¹⁹⁹. They experience a 'dual crisis' when the normative developmental stressors derived from the tasks transitioning from adolescence to young adulthood²²¹ combine with the challenges associated with an unexpected cancer diagnosis²²².

While research has shown many young people diagnosed with cancer learn to adapt to life with illness and find positive ways to cope and make meaning of this unanticipated experience^{55, 223, 224}, there is nonetheless a broad ranging international research consensus that young people who develop cancer at this pivotal stage in the life-course are at risk of developing psychosocial problems both during and after the cancer treatment trajectory. This suggests there is a need for a better understanding of the constituents of age-appropriate care, effective psychosocial support and provision of supportive interventions during and post-treatment^{16, 225-229}.

The risk of developing psychosocial difficulties is hardly surprising given the well-documented wide-ranging array of significant challenges that young people with cancer must face. These include significant restrictions to everyday life, the physical experience and adverse effects of illness and treatment (both short and longer term), social identity challenges, relationship and life course disruptions, and loss of control while coping with the life-threatening nature of many cancer diagnoses and managing ongoing existential uncertainty and isolation^{55, 74, 230-234}. There is also a recognition that a single uniform experience of cancer does not exist with variable challenges and coping strategies, depending on the cancer site, type and duration of treatment protocol, prognosis, age, gender and each young person's unique physiological and psychological response to presenting stressors in the context of their family and peer relationships and broader social support networks^{105, 235}.

GOOD OUTCOMES ARE MORE THAN SURVIVAL

The Children and Young People's Improving Outcomes Guidance (CYPIOG) recognised that good outcomes

'encompass more than improved health, in terms of survival, mortality and morbidity'¹. These guidelines specifically note that improving outcomes for young people with cancer must also include a focus on quality of life, self-esteem, participation in daily life and the ability to mature successfully to adulthood. Rehabilitation services for example, are advised to seek 'to improve overall physical, emotional, social and educational outcomes during and after treatment'¹ and supportive care should aim to 'help the patient and family to cope with cancer and its treatment throughout the cancer journey...to help the patient maximise the benefits of treatment and provide the best quality of life'¹.

While these broader outcomes are articulated in a number of ways in the CYPIOG¹ and ascribed different emphasis depending on the particular strand of care delivery, it all points to the importance of extending our vision as service providers to include not only the disease and its medical treatment but also the experience of the ill young person and their holistic health and well-being as they progress through treatment and beyond. This emphasis on promoting a holistic sense of well-being is all the more important with the recognition that advances in cancer treatment have led to improvements in survival rates²³⁶ but often with complicating treatment late-effects^{225, 237}. With cancer increasingly becoming thought of as a chronic disease, which can result in long-term disabilities requiring on-going care and support²³⁸, it is imperative to remember that for many young people with cancer, survival is 'not necessarily a simple end to a cancer story'²²⁵.

CURRENT AND FUTURE WELL-BEING: DEVELOPING RESILIENCE

This broader emphasis on holistic well-being is affirmed in TYA literature, which acknowledges that for young people with cancer undergoing treatment the problem is not solely future survival but 'survival in the present'^{239, 240}. In a TYA survey in the UK, 73% of young people rated quality of life and survival as equally important²⁴¹. This focus on the present concurs with Thomas *et al.*'s²⁴² conclusion that while young people have 'an increasing capacity for abstract thought enabling the realisation of concepts that generally lie outside their immediate experience, such as death, most nonetheless place greater emphasis than mature adults on the immediate demands of the present, rather than future concerns or possibilities'.

While enhancing TYA well-being during treatment is therefore a valid outcome in its own right, it is also thought to have the additional potential effect of increasing the capacity for future well-being as a young person learns new ways of coping with illness and treatment-related challenges. Psychosocial interventions to promote well-being in the early stages of treatment may therefore assist with longer-term coping and the development of resilience, defined as a process for identifying and developing resources and strengths to manage inevitable stressors^{243, 244}. It is in this context that the promotion of young people's well-being and resilience are considered key healthcare goals.

POSITIVE HEALTH CONCEPTS: FROM RISK TO RESOURCE

TYA studies have been criticised for over-emphasising pathology models of addressing psychosocial adjustment, which are thought to reduce complex lived experience into predetermined psychological variables such as measures for anxiety and depression²⁴⁵. Researchers have suggested there should be a greater use of meaning-based and positive health concepts to understand TYA experience to explore how care provision might be supportive^{246-248 233, 243}. This shift mirrors developments in the broader public health policy arena, which increasingly utilises positive health concepts such as 'well-being' and 'resilience' when a broad definition of health outcome is required. Both concepts adopt a strength or asset-orientation, which shifts emphasis from illness and disease to wellness. This recognises a person's well-being as being a state of constant flux and well-being promotion as a process of utilising resources to manage unavoidable stress²⁴⁹. A person's well-being is therefore maintained by a balance of stressors and resources, which are thought to be embedded and shaped by an individual's unique psychosocial and cultural context^{243, 249}. In this way the capability of populations and individuals to participate fully in the health development process is also accentuated²⁵⁰.

WELL-BEING

While the concept of well-being is recognised as a complex and contested construct it is increasingly applied to public health policy as a 'potentially unifying concept for health improvement, which encompasses a range of medical and non-medical priorities, differing values and objectives that in the real world cannot be separated'²⁵¹.

Although conceptually distinct and operationalised in a number of ways, well-being as an integrated term has been found to encompass subjective well-being constructs such as happiness, wellness, contentment and joy and psychological well-being constructs such as autonomy, engagement, confidence, self-esteem, self-acceptance and life satisfaction, which is closely associated with 'quality of life'²⁵²⁻²⁵⁶. Well-being as a single multidimensional construct is considered a combination of 'feeling good' and 'functioning

*effectively'*²⁵⁷ and encompasses physical, psychological, social and emotional components, including self-esteem, quality of life, participation in life and positive social relationships. The importance of well-being concurs with the underpinning philosophy of the World Health Organisation (WHO) which defines health as 'a state of optimal physical, mental, and social well-being and not merely the absence of disease and infirmity'²⁵⁸.

RESILIENCE

Resilience too has a number of theoretical conceptualisations. It is generally considered a dynamic process involving an interaction between both risk and protective factors, which are internal and external to the individual. These act to mediate the effects of adverse life events²⁵⁹. It is important to note that resilience does not imply an invulnerability to stress but rather an ability to recover from challenging events with support²⁶⁰. Some conceptualisations focus on resilience as an *outcome* emphasising the maintenance of functionality, while others focus on resilience as a *process* of adaptation to a risk-setting, seeking to understand the mechanisms that act to modify any negative impacts and the developmental processes by which young people successfully adapt²⁶¹. This process orientation leads to the identification of resilience promoting factors, which are generally considered at three different levels: the individual level (resources, competencies, talents and skills); social level (family and peer network); and societal-level (e.g. community, school, support services). Resilience as a social ecological concept²⁶² defines resilience as more than an individual's capacity to cope and recognises that for young people with complex needs living in adverse circumstances (such as young people with cancer), the design and delivery of professional support systems are crucial²⁶³.

PROMOTING WELL-BEING AND RESILIENCE IN YOUNG PEOPLE WITH CANCER

Over recent years these positive health concepts and others such as coping, adaptation, adjustment and quality of life have been adopted and adapted by TYA cancer clinicians and researchers as a means of theorising about how healthcare systems can provide age-appropriate care. A range of interventions are proposed to support young people with cancer in ways that expressly take account of what is important to young people and build on existing individual and social resources in order to enhance an overall sense of wellbeing, both in the short and longer term^{16, 105, 172, 224, 243, 246, 247, 264}.

THE ROLE OF ALLIED HEALTH AND PSYCHOSOCIAL PROFESSIONALS

While many ways of promoting well-being and resilience are discussed in other chapters of this publication, including the provision of age-appropriate care (**Chapter 4**) and holistic and

supportive care (**Chapter 6**), this chapter explores common psychological, psychosocial, social and physical challenges experienced by young people with cancer and headlines the unique contribution of allied health and psychosocial professionals such as Psychologists, Physiotherapists, Occupational Therapists (OT), Social Workers and Youth Support Co-ordinators in supporting young patients' well-being and promoting resilience. Access to appropriately skilled professionals is identified as a vital component of TYA cancer care in the CYPIOG¹, which stresses the need for timely input at all stages of the cancer pathway including diagnosis, acute care, supportive care, rehabilitation and palliative care.

PSYCHOLOGICAL WELL-BEING

MENTAL HEALTH AND YOUNG PEOPLE

Unidentified mental health difficulties in young people can lead to educational disruptions resulting in underachievement, substance misuse, self-harm, suicide, violence and poor sexual health²⁶⁵. Mental health problems are significant in adolescence and young adulthood, affecting around one in ten children and young people and rising to one in five young adults²⁶⁵. Mental health disorders in young adults are surprisingly common²⁶⁶ with three quarters of all lifetime cases of psychiatric disorders beginning by the age of 24 years²⁶⁷. Interestingly, although young adults as a whole are the most likely age group to develop mental health problems, they are the least likely to recognise that they have a problem that might benefit from intervention²⁶⁸. They are also the most likely to think that they should handle mental health problems by themselves²⁶⁹. This can result in delayed intervention with recent research indicating a ten-year delay between young people displaying first symptoms and getting help²⁶⁷. These are considered missed opportunities for early intervention²⁶⁵, which could significantly reduce life-course impairment²⁷⁰.

MENTAL HEALTH AND YOUNG PEOPLE WITH CANCER

Some mental health difficulties are thought of in terms of a stress-vulnerability model²⁷¹ where any person who is under enough stress could be tipped into experiencing symptoms reaching the threshold for a mental health diagnosis. While it is to be expected that young people with cancer will experience mental health challenges associated with the changes in their circumstances and living with the uncertainty of illness and perhaps debilitating and restricting treatment protocols, if any symptoms are sustained or start to impact significantly on their everyday lives, consultation with or referral to a Clinical Psychologist or Psychiatrist is important. MDT members should know who the Clinical Psychologists and Psychiatrists are and how to refer patients to them.

CLINICAL PSYCHOLOGY: WORKING WITH MENTAL HEALTH DISORDERS AND PROMOTING TYA RESILIENCE

Clinical Psychologists working in cancer do not only work with diagnosed mental health disorders they can also help

foster young people's resilience, help them adjust to new circumstances, tolerate treatments, communicate with their family/friends about difficult topics, support them through complex decision-making and help them process their thoughts and feelings. Some members of the MDT such as OTs also have specialist mental health training and may be able to offer valuable interventions for mild to moderate emotional difficulties such as anxiety, low mood, low self-esteem, and anger.

This section not only addresses mental health *disorders*, but also suggests how healthcare professionals can support young people before their distress reaches a critical level. Research indicates how young people value the support they receive from all staff members involved in their care, including medical, nursing, social care, allied health professionals and auxiliary staff^{16, 272}. Some 'top tips' are provided to help practitioners to:

- Support young people to manage their distress effectively;
- Become more aware of when to refer a young person for more specialist support;
- Notice their own feelings and look after themselves.

As discussed in **chapter 2**, when young people are diagnosed with cancer it often disrupts their typical developmental pathways, physically, socially, psychologically and educationally/vocationally. Young people vary widely in their emotional maturity, their independence in decision-making, their support network and the issues that are most significant to them. Cancer affects everybody in the young person's multiple systems, e.g., family, school/university and friendship groups. In particular, it is known to greatly impact parents and families, whose own well-being can be compromised^{273, 74}. Relationships with families and parents are noted as a great resource as well as a source of distress and conflict^{235, 275}. When assessing young people's psychological and psychosocial needs, it is therefore important to take all of these factors into consideration and liaise with the wider MDT, in particular the Social Worker who is likely to know important family members.

PSYCHOLOGICAL DISTRESS

Research in relation to distress in young people with cancer has reached varied conclusions. Allen *et al.*²⁷³ found 38% of 12-20 year olds reached diagnostic criteria for depression at the time of receiving the cancer diagnosis, with recent research reporting higher levels of distress in the TYA population as compared with the general cancer population^{276, 277}. However, other research proposes that while higher levels of anxiety and depression were present at diagnosis in comparison with healthy peers, over time young people found ways to adapt to illness with reports of psychological well-being steadily

improving and displays of post traumatic growth²²³. It should also be noted that distress in and of itself is not necessarily a problem as young people functioning well under high stress often show higher levels of emotional distress compared to low stress peers^{278, 279}.

Given that depression and anxiety are common psychological diagnoses in adolescence²⁸⁰ and the challenge of encouraging young people to seek timely professional help²⁸¹, it is advisable for health and social care professionals to be alert to symptoms of significant psychological distress in the TYA cancer population. Symptoms of anxiety and depression can include²⁸²:

- Lack of interest in previously enjoyable activities;
- Feelings of hopelessness;
- Social withdrawal;
- Feeling anxious and tearful;
- Sleeplessness;
- Change in appetite;
- Lack of motivation/apathy;
- Finding it difficult to concentrate;
- Having unexplained aches and pains;
- Having suicidal thoughts;
- Self-harming.

HOW TO IDENTIFY PSYCHOLOGICAL DISTRESS

In the context of becoming diagnosed with cancer at a young age, many of the above symptoms are to be expected and may also be the side-effects of some treatments. This can make it difficult to distinguish whether the young person requires better symptom management or support from a mental health professional. A good place to start is by trying to engage the young person in a conversation about how they are coping to give an indication of what might be most helpful to them. If symptoms continue for more than two weeks consistently it is usually advisable to consult a mental health professional.

Recognising symptoms early will allow timely help and support from healthcare professionals. Young people are more inclined to seek help for mental health problems if they:

- Have some knowledge about mental health issues;
- Have some knowledge about the sources of help available to them;

- Have established trusting relationships with healthcare professionals.

The relationship between the young person and key members of the TYA MDT is critical in helping them feel able to talk about the emotional aspects of their experience and feel as though they have been heard and understood. This can be achieved by encouraging emotion-talk and effective listening. (See also Chapter 6).

Helping young people talk about emotions

In the same way we might assume that we should only talk to our dentist about our teeth, some young people might assume that they should only talk to nurses or other healthcare professionals about medical or physiological issues so if not asked directly how they are feeling emotionally, they are unlikely to raise this issue as they may believe it is not relevant to the professional role.

- A useful way to open conversations with young people is by explaining that psychological distress is "common" in cancer rather than "normal". It may not be 'normal' for the young person in the context of their life but can be helpful to know that others share similar feelings.
- It can feel less pathologising to use terms such as "when low mood is around" or "when you are experiencing low mood" rather than "you ARE depressed". This avoids implying there is a pathology located inside that individual, which could be understood as a personal weakness that they can do little about rather than an understandable response to their new and challenging circumstances.
- When enquiring about a young person's emotional state, try not to ask "how are you feeling?" because it can be hard for people to reflect on how they are in that current moment. It is also a social nicety and we all know the socially expected response is "fine thank you. How are you?" The young person is more likely to open up if you ask "how have you been feeling since I last saw you?" This is because it is easier to reflect on the past, e.g., "I WAS feeling tearful" versus "I AM feeling tearful". It sounds less like a social formality and as though you are genuinely interested, which gives them permission to talk about their feelings.
- It is useful to think back to the last time you felt you were not being listened to effectively. What was the person doing? Were they in a rush? Did they interrupt you? Did they change the subject? Did their eyes glaze over? Although busy professionals all do this from time to time, it signals to the young person that they are not interested in listening to them and as a result they might not be willing to share their distress and miss out on receiving support. When busy, it is difficult to always provide effective listening. In such situations it can be useful to say to the young person at the start "What

you are saying sounds really important. I actually only have 10 minutes right now and what you have said so far sounds like it is deserving of more time so can we arrange to meet later on or tomorrow when I will have more time to properly sit and listen?”.

- Often it is reassuring for young people to know how long a healthcare professional has with them so they are not worrying while they are talking that they are using up time that the healthcare professional does not have to spare. Being transparent about this at the start also allows the healthcare professional to be fully focussed without having to feel frustrated about closing down the conversation so they can leave.
- Encourage young people to be open about their psychological experience and emotions by explaining that it is *understandable* that they might feel uncharacteristically tearful or anxious given their diagnosis, treatment, and uncertainty about the future but this does not mean that they cannot receive some support to help them manage these feelings. Pain is expected but we still treat it with analgesia. Psychological pain is similar and can be talked through with a healthcare professional as there are a lot of psychological tools and strategies that can help.

ANXIETY

Many young people (and their parents) experience anxiety throughout their cancer journey²⁷¹. While some anxiety is

to be expected and appropriate in the circumstances, it can become problematic when it starts to interfere with the young person's ability to engage in everyday life, such as struggling to go outside or maintain friendships. It is important to remain alert to the possibility that prolonged, heightened anxiety can escalate to a point where it becomes a problem in itself, which can lead to panic attacks, health anxiety, paranoia, obsessive compulsive disorder, phobias, difficult family communication and social interaction. Anxiety may happen in specific situations or be associated with particular tasks such as being in public places (agoraphobia) or being with other people in social situations (social anxiety). Anxiety may present in specific ways such as panic attacks, which can be debilitating and frightening.

Family members are likely to take on specific roles and may be holding onto different aspects of distress^{273, 274}, which can manifest in different coping strategies, some of which are more or less helpful. For example, it is commonplace for parents to worry about their child, and the young person in turn to worry about their parents worrying. This process can become a vicious and counter-productive cycle as family members seek to protect and shield one another from their own anxiety. Some young people/family members might externalise their anxiety by showing their worry and seeking repeated reassurance from different members of the MDT, in effect they are asking the professionals to 'contain' their anxiety for them. Others might show their anxiety through irritation and aggression. It is important to remember that each person is coping with a large amount of uncertainty and loss of control.

TOP TIPS

to support emotion-talk and effective listening

- Remember to ask how young people are coping emotionally not just physically, otherwise they may assume they cannot talk to you about their feelings.
- Help young people understand that being distressed or feeling low or worried after a cancer diagnosis is 'normal'.
- Help young people identify any fears or concerns so you can clarify any unfounded fears and ensure they get access to accurate information.
- If you are busy, state this and arrange another time to come back and take time with the young person. Make sure you honour this commitment.
- Explain that there are services available to help young people talk about their feelings and help them get through treatment.
- Help young people identify other trusted adults they can talk to.
- Appreciate their courage in speaking to you and encourage them to keep reaching for support.

TOP TIPS

when working with anxiety

- It can be useful to name anxiety early on and help the young person, their friends and family think about the function of worry for them and how they manage it. It can be helpful to name these processes in front of everyone.
- Remember that it is normal for family members to seek to protect and shield one another from their own anxiety.
- Supporting young people to think about the type of support they would like from friends and family can be helpful. Encourage the young person to directly request this form of support.
- Encourage young people to tell their friends whether they want them to mention cancer and ask questions or if they would prefer not to talk about it, whether they wish to be contacted daily and by what method. This helps the young person's friends know how best to support them rather than feeling awkward and withdrawing from the young person.
- It can also be helpful to ask young people to think back to other difficult times in their lives and ask how they coped then with uncertainty.
- Help draw young people's attention to what they **CAN** do and where their strengths lie.

Responding to psychological distress: what can you do?
Once the young person feels secure enough to disclose their feelings, what should the professional do? Below are some interventions which can help.

Anxiety management

Advice and education on what anxiety is and methods for managing anxiety are **essential** and can be provided by a Psychologist or an OT who has additional mental health training.

Psychoeducation: It can be useful to provide some psychoeducation about why anxiety exists i.e. the 'fight or flight' phenomenon, to help the young person avoid misinterpreting the physical symptoms of anxiety as having a sinister cause. This can sometimes happen with panic attacks. An explanation of anxiety that a healthcare professional could offer the young person is: If a caveman saw a lion he would feel anxiety, which would flood his body with adrenaline to make his heart pump faster and his muscles fill with blood ready for action so that he could either run away quickly or prepare to fight the lion. The physical symptoms of anxiety are our body's way of preparing us to face a threat but in this setting it is counter-productive because the threats or triggers for anxiety

are doctors or chemotherapy or even the word 'cancer' and you cannot run away or fight, so you need to manage the physical symptoms of anxiety differently. Helping the young person to understand their experience of anxiety in this way can help reframe their racing heart as benign anxiety rather than a heart attack and can help them calm down more readily.

Relaxation and breathing exercises:

Young people can be taught relaxation techniques or shown breathing exercises for anxiety where the young person exhales for 2 seconds longer than they inhale to reduce the amount of oxygen in the blood. For some of the younger people it can be helpful to encourage them to blow bubbles to regulate their breathing (e.g., inhale for 5 seconds, exhale for 7). Additionally, people can imagine blowing all of their tension and fears into the bubble which then floats away. It is useful to explain that breathing in this way effectively reduces anxiety at a biological level as well as giving the young person a feeling of control and distracting them from the anxiety trigger by focussing on the breathing task. This can help calm the young person if they are acutely anxious or if they are beginning to have panic attacks generally.

'Worry time': It can be useful to suggest that if the young person is awake at 3 am worrying they should write down the worry then focus on it at a set 'worry time', i.e., in the morning when they are able to think more rationally and talk it through with another person rather than ruminating alone in the dark.

Diary: Writing down worries can make people feel like they are taking control of their anxiety. Often naming something and seeing it written down can make it seem more manageable. It can also feel helpful to have expelled the worry from one's mind onto a page where it will stay safe, not be forgotten and can be addressed properly at their next appointment with you.

Identifying triggers: Recognising thoughts that trigger anxiety and helping young people identify strategies to manage them.

Challenging avoidance: More specialist support can use a graded approach with the young person to challenge anxiety and avoidance of activities, such as slowly building up time in a place where the young person feels anxious.

Helping with depression

Get to know the young person: Just listening to a young person and empathising with their distress can make them feel less alone and more understood. For professionals who are going to have a lengthy relationship with a young person, it can be useful at the very beginning to tell them that you would like to get to know about them and their lives before they were diagnosed with cancer, to try to help them feel connected to the positive aspects of their pre-cancer identity.

Plan small tasks: In addition, it can be useful for the young person to plan daily activities. If the young person plans *small, achievable* tasks each day, they will obtain a feeling of success and accomplishment. The tasks can be incredibly small but it is important for the young person to retain a sense of purpose and have access to feelings of satisfaction.

Promote independent functioning:

Normative young adulthood typically involves the development of increasing independence from one's parent/family system, so maintaining some independent function and self-care tasks can be helpful. Some of the information about psychosocial well-being later in this chapter and the role of the OT and others may be helpful in this regard. However, it is also important to acknowledge that the young person has undergone a change in their self-perception into the role of a 'patient' and may therefore go through phases of needing to revert back to earlier dynamics of dependence with their parents, even perhaps to the point of sleeping in the same bed for a few nights. It is important not to pathologise this and allow families time and space to find a new way of adapting to the changing needs of the young person. If the young person does not wish to maintain their independent functioning it is likely that this is because it plays a protective function for them at that point, so it is advisable not to push them too hard if they are resistant. Every young person is different.

Physical exercise

Physical exercise is usually positive for low mood because it releases endorphins, leads to a sense of achievement and often gives the young person access to fresh air and other people. Exercise tasks should be set up with the support of the physiotherapist as small, achievable goals to give the young person the experience of success, e.g., a 3-minute walk in the garden or from one end of their road and back or some arm stretches in their bed. It is important to validate this achievement *in the context of their current ability*.

Psychoeducation: It is useful to explain that at times of low mood, our thoughts, emotions, body and behaviour all influence one another in a negative spiral, e.g., when our body feels heavy and tired, our mood can feel flat and heavy and this mood tends to prime our thoughts to fall in sync and be somewhat negative or sad. Our behaviour is to withdraw socially and lie on the sofa with our sad thoughts. This is how low mood feeds itself. So although it can feel counter-intuitive to do anything active like a walk, it is helpful to break the cycle

of low mood. As evidence to support this a professional could design an experiment with the young person where they rate their mood out of 10 before doing some exercise then again after to see if it has changed.

Be patient:

There is a limit to what can be done to reduce low mood when a young person is facing cancer. The young person might need space to just 'be' with their feelings of sadness but in the knowledge that there is someone who is interested in them, understands that they are feeling sad at the moment and can organise to be available to talk with them or access professional support at another time should they wish.

Problem solving

Help young people generate their own solutions:

Problem solving is a key part of how professionals can offer support to a young person. They usually have enough authority figures telling what they 'should' be doing, so it is more effective to help young people generate their own solutions. This can be achieved by asking questions about how they have coped in the past, what is helping them cope now, what resources and people are around for them and what they themselves want and CAN do.

Help make problems specific and measurable:

For example, "if it was one month from now and the impact this problem has on your life had reduced and you were feeling happier, what would be different and how would I know?". If a young parent feels that they cannot look after their child like they used to, help them to think about other ways they can show their love and care for the child, for example "you cannot lift your child up right now but are there other ways you can care for her, such as asking her to sit on your lap for a cuddle or reading her a story?".

Find out what young people enjoy:

It is important to remind young people (and their partners and family members) to be kind to themselves and try to find "pockets of happiness" each day in amongst the sadness and difficulty, where they treat themselves to something they enjoy, e.g., a bubble bath, a piece of music, a foot rub or a favourite meal.

TOP TIPS

for helping young people manage psychological distress

- If you see a young person is feeling low, don't ignore it. Ask how they are coping and help them talk about their feelings.
- Remember to ask young people how they are coping emotionally as well as physically. Asking directly ensures young people know that they can talk with healthcare professionals about their emotional well-being as well as their physical health.
- Enquire about family members' emotional well-being also. Supporting family members will have a beneficial effect on the young person also.
- Show an interest in getting to know the young person. Spend some time finding out about their lives, important people and what they enjoy. This can help the young person feel listened to and that illness has not taken over their lives or identity.
- Help the young person remember the good aspects of their life and what they can do, or are looking forward to.
- Listen to the young person's worries and empathise. Help them feel they are not alone and you can help them access appropriate support if needed.
- Draw on the expertise and support of the wider MDT team. Contact with the physiotherapist, the OT, the Social Worker or the Youth Activity Co-ordinator may help the young person get through treatment.
- If the young person's low mood and distress persist and is interfering with their everyday life, refer to the Clinical Psychologist for more specialist mental health support.
- Help the young person understand that distress is normal in the context of a cancer diagnosis, and with the right support they will find ways to get through this tough time.

Onward Referral

Psychological distress is an understandable and appropriate reaction to a cancer diagnosis, which does not always require onward referral to specialist mental health services. Sometimes just telling their Clinical Nurse Specialist or another health or social care professional and knowing that they understand can help the young person cope. However, if a young person's psychological distress reaches a worrying level or manifests in unhelpful or even harmful behaviours, the MDT should always consult or refer to Psychology or Psychiatry for supportive interventions. It is important that MDT members are aware of these referral pathways and are familiar with the referral process. Consent should always be gained from the young person involved, unless they are deemed to be at risk of immediate harm. Don't be afraid of mentioning psychology to the young person. If you are concerned that the young person might think you believe they are 'mad' or there is a stigma surrounding psychology, it can be helpful to mention this yourself and ask if they have such concerns. Research with young people indicates that many would have wished for unhindered access to psychological support, with some who had sought support reporting the referral process as difficult to manage¹⁶.

OTHER IMPORTANT MENTAL HEALTH PROBLEMS

Self-harm

The term 'self-harm' is used when an individual intentionally injures or harms themselves. Self-harm is usually a private and always a sensitive often misunderstood and confusing behaviour. As a result, there is a shortage of reliable information about self-harm in young people that does not result in the use of accident and emergency or other health services. It is estimated that young people presenting to hospitals represent less than 10% of the adolescent population who self-harm²⁸³. The available data suggests the majority of people who self-harm are aged between 11 and 25 years^{266, 284}. A large study found that although 7% of 6,020 school pupils had self-harmed in the previous year, only 13% of those had presented to hospital²⁸⁵. Young people who self-harm are between 50-100 times more likely than the general population to die by suicide in the future^{286, 287}.

Reasons for self-harming

In a population based survey of 1,258, 18-20 year olds in Scotland²⁸⁸ the most common reasons given for self-harm were:

- Relief of anger;
- Relief of anxiety;
- Wanting to forget about something;
- Desire to end life (this reflects suicidal intent discussed below).

Other reasons can include²⁸⁹:

- To punish themselves;
- To bring their distress to the attention of others.

It is imperative that health and social care professionals working with young people are alert to the possibility of self-harm and are able to refer promptly to Psychiatry or Clinical Psychology.

Methods of self-harm

The following have been reported as the most common methods of self-harm amongst young people²⁸⁸:

- Cutting
- Scoring
- Scratching
- Taking dangerous tablets
- Burning (rare)
- Punching (rare)

TOP TIPS

when concerned about self-harm

- Tell the young person you are concerned for them and reassure them that with help they can find safer, alternative ways of coping with adversity.
- Ensure the young person is aware of the risks of self-harm.
- Recognise signs of distress and talk openly with the young person about how they are feeling.
- Listen to the young person's worries and problems and take them seriously.
- Help them identify any aspects of their lives that are going well.
- Check out who else is aware of the young person's self-harm.
- Help the young person share this information with trusted adults in a sensitive and supportive manner.
- Ensure the young person is referred to appropriate mental health services as soon as possible.

Suicidal Ideation

After cardiovascular disease and cancer, suicide is the next most common cause of death²⁹⁰. Suicide is the leading cause of death for men and women aged 20-34 years, accounting for 26% of male fatalities and 13% of female deaths²⁹¹. Suicide rates are consistently highest among young men and more than double in 20-24 year olds compared to 15-19 year olds²⁹². Young people who attempt to take their own lives often feel hopeless or do not know where or how to get help. Young adults aged 15-30 diagnosed with cancer have an increased risk of suicide attempts compared to age-matched peers in the general population. This could be because young people have not had long enough to develop effective coping strategies for stress²⁹³.

The risk of suicide is higher when a young person^{294, 295}:

- ☐ Is male;
- ☐ From a lower income group;
- ☐ Has untreated depression or when they have a psychiatric diagnosis;
- ☐ Is self-harming or has a history of self-harm;
- ☐ Is misusing drugs or alcohol;
- ☐ Has previously attempted or planned suicide;
- ☐ Has a relative or friend who died by suicide or attempted suicide;
- ☐ Is socially isolated;
- ☐ Is involved with the criminal justice system;
- ☐ Feels hopeless;
- ☐ Has a history of abuse;
- ☐ Has painful or physically disabling illnesses including chronic pain;
- ☐ Is LGBT (lesbian, gay, bisexual, transgender) identified.

Talking about suicidal thoughts

Asking the young person if they have ever thought about ending their life will NOT cause them to carry it out or put the idea in their head. Instead it will ensure a young person knows that they can talk about these feelings with healthcare professionals and access support. A useful response can be to state that suicidal feelings are "worrying" to show them the importance of what they are saying and communicate that you are taking them seriously.

There are various aspects of suicide that are worth asking about but it is important to **always refer** to mental health services or consult a psychiatrist. Here are some useful areas to include in questions and conversation about suicidal thoughts:

Ideation:	Ask directly if they have thought about ending their life or killing themselves. Do not be afraid to use these words.
Intent:	Ask about whether they intend to end their life.
Plans:	Ask whether they have considered how they would kill themselves. Find out if they have access to means e.g., prescription drugs, ligature etc.
History:	Ask if they have ever felt like this before or attempted to kill themselves before. If so how, or if not, what stopped them? Has anyone close to them ever attempted or died by suicide?
Protective factors:	What would stop them from killing themselves, e.g., family, religious beliefs?
Knowledge of resources:	Ask the young person what they can do if they feel unsafe. Ask if there is anyone else who knows they are feeling this way. Help them to identify trusted adults in their lives who would be able to help. These can be people in their informal personal network or trusted professionals they have got to know. Tell them the options, e.g., speak to a loved one, speak to a trusted adult, go to accident and emergency, call an ambulance, call the Samaritans (give them the number or one for another crisis helpline), call NHS Direct, contact their GP

THE MOST IMPORTANT THING TO DO IF SOMEBODY EXPRESSES SUICIDAL THOUGHTS is to **SHARE THE INFORMATION**. Document everything and share the information, create a safety plan with the young person and the other health and social care professionals providing care to them. It may be important to share concerns with the young person's family or loved ones. This should be carefully negotiated with the young person first and where possible consent sought. If the young person states they do not wish to tell their family, enquire what they are worried about. Sometimes young people's worries are unfounded. Encouraging the young person to reach out to trusted adults can be a good first step in accessing support. It is important however to then follow-up with the trusted adults and the young person to support and facilitate access to appropriate professional care.

TOP TIPS

when concerned about suicidal thoughts

- Don't be afraid to ask about suicidal thoughts, plans and past attempts! Your question will not put the idea in a young person's mind.
- Teams working with young people should be mindful of a young person's mood throughout treatment and be aware of any history of self-harm or suicidal thoughts/actions.
- Suicidal thoughts should always be taken seriously.
- **Always** consult with senior colleagues and together decide the most appropriate plan of action.
- Explore with the young person whether they have made suicide plans.
- Help the young person identify trusted adults in their lives who they can share their feelings with.
- Always follow-up with trusted adults to ensure they are aware of the young person's suicidal thoughts or plans.
- Help the young person create a safety plan.
- If a young person has suicidal thoughts, they should be referred to appropriate mental health services as soon as possible.
- If a young person is actively suicidal, they may require an immediate mental state assessment.
- Be familiar with your organisation's suicide prevention policy and the numbers for on-call psychiatry and other local resources.
- Safety planning and risk of suicide require consistent reassessment on every contact until the risk has abated and stabilisation achieved.

PHYSICAL WELL-BEING

COMPROMISED WELL-BEING: THE PHYSICAL SIDE-EFFECTS OF CANCER AND TREATMENT

The specific diseases and treatment regimens that young people with cancer experience cause a vast array of physical side-effects, both in the short and long-term.

At their most profound, physical deficits can limit a young person's ability to function independently and to engage in normal daily activities. At a time of life when peers are starting to forge independence from parents, spending most of their

time with friends and making decisions about their future, this can be devastating. Even seemingly minor deficits can impact on a young person's everyday life and social interactions.

Young people have identified physical limitations as their greatest unmet need during treatment, which also impacts their psychosocial well-being^{296, 297}. Addressing physical deficits can help reduce the physical burden of cancer in young people and minimise the disease impact on the young person's life.

PHYSIOTHERAPY: PROMOTING WELL-BEING THROUGHOUT THE ILLNESS TRAJECTORY

The aim of the Physiotherapist working with young people with cancer is to enable a minimum level of dependency and to optimise quality of life regardless of life expectancy. This involves directly addressing the physical side-effects of cancer and its treatment and facilitating an active lifestyle in order to maximise general health and well-being and prevent secondary complications.

Physiotherapy with young people requires a flexible approach. Having the service available later in the day than standard physiotherapy hours (e.g. 10am-6pm instead of 8am-4pm), having an informal referral system including self-referral and using text message and email to communicate are all aspects of service delivery noted to increase treatment compliance and engagement. Working closely with the wider

"Physiotherapy is useful for relieving pain in areas such as my back and legs."
(male, aged 22, acute myeloid leukaemia)

"Physiotherapy helped me walk again and get my leg stronger. Now I almost feel like my good old self again!"
(female, aged 17, following limb salvage surgery for osteosarcoma)

"No matter what happened (and a lot has) physiotherapy always made me feel there was something I could do to help myself and I left feeling better afterwards"
(male, aged 20, following stem cell transplant for acute myeloid leukaemia)

MDT allows regular exchange of information, which will help tailor physiotherapy input appropriately.

The physical side-effects of cancer and its treatment can extend well beyond treatment completion. Survivors of young adult cancers have lower quality of life than their peers and more days of poor physical health²⁹⁸. On-going physiotherapy is therefore vital to continue addressing physical deficits and to maximise quality of life.

Groups who will be in particular need of on-going physiotherapy include:

- *Those who have been treated for brain and central nervous system lesions:* Their needs will often be complex and neurological recovery (where possible) is slow. For severely affected individuals input may be required from specialist neuro-rehabilitation teams in dedicated units. Appropriate discharge planning and community support is vital for such patients. For those with less extensive neurological deficits it is important to have access to physiotherapy as and when needed.
- *Those who have had limb salvage surgery or amputations:* Rehabilitation following these operations is lengthy and complex and young people often aren't well enough to fully engage with physiotherapy until their chemotherapy treatment is completed. Referral to the individual's local musculoskeletal physiotherapy service or wheelchair and prosthetic centre is needed to ensure input continues after cancer treatment ends.
- *Those who have had a stem cell transplant:* Due to the intensity of this treatment individuals may become extremely deconditioned and lose independent function. Graft versus host disease can cause musculoskeletal deficits and individuals are at risk of repeated infections such as chest infections. Physiotherapy may be required to address these issues.
- *Those suffering from osteonecrosis as a result of steroid treatment:* This is a disabling orthopaedic condition causing pain, joint restrictions and reduced mobility. In young people this is mainly seen following treatment for leukaemia particularly acute lymphoblastic leukaemia. Physiotherapy is required to minimise symptoms and maximise function.

“Recovering from cancer is a difficult process and even though it's a year since my treatment finished, I still feel very weak and tired a lot of the time, and as a consequence, I don't really get out much.”

(male, aged 23, following treatment for rhabdomyosarcoma)

TOP TIPS

for promoting physical well-being

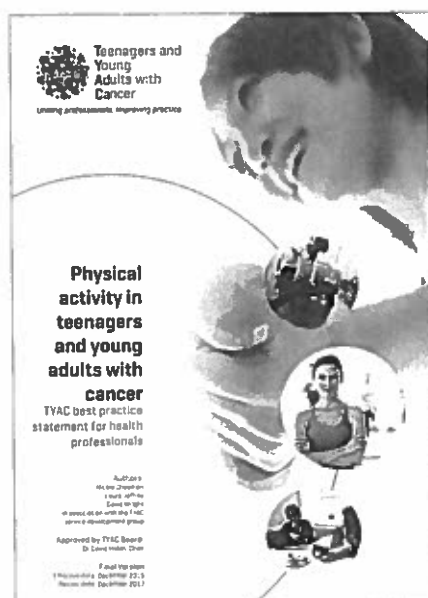
- Ensure that physical ability/function is part of the holistic assessment process so that timely referral can be made to physiotherapy.
- Promote basic physical activity throughout the patient pathway where possible.
- Provide opportunities for exercise during and after treatment, either through specialist professionals or by engaging services from the young person's local community.
- Ensure access to physiotherapy continues into survivorship.
- Consider referral to physiotherapy throughout the patient pathway, including end of life care.

Even as the goals of cancer treatment change to palliation and end of life care, physiotherapy can help young people adapt to their changing physical ability and work towards their personal goals. Input may include providing equipment and advising on techniques to facilitate independent mobility and function where possible, positioning for pain relief and breathlessness management.

PHYSICAL ACTIVITY AND EXERCISE

Physical activity is an essential component of a healthy lifestyle. In the general cancer population regular physical activity improves quality of life, physical and psychosocial function and has been linked to increased disease-free survival^{299, 300}. Regular physical activity is recognised as an effective way for people during and after cancer treatment to minimise the side-effects of their disease and treatment and to optimise general health status. Moderate levels of physical activity during and after cancer are recommended by leading national bodies^{299, 301, 302}.

However, young people during and after cancer treatment have tended to not do enough physical activity³⁰³. The level of activity has been shown to be below that recommended to maintain basic health and to prevent common long-term conditions such as diabetes mellitus, coronary heart disease and obesity^{302, 304, 305}. Given the potential number of years that young people may live with and beyond cancer, plus the elevated risks for health problems due to the side-effects of cancer treatments increasing levels of physical activity and exercise is essential to maximise health and well-being.



To download the Best Practice Statement Physical activity, please go to the TYAC website: www.tyac.org.uk

Young people themselves recognise this need, with 88% of young people at the 2013 Find Your Sense of Tumour conference feeling that their treating hospital should provide them with exercise advice. Only 28% reported having access to organised exercise and 32% had received exercise advice³⁰⁶.

“Really great fun, met new people and it’s a good way to gain my energy back”
(female, aged 20, following participation in an exercise scheme after treatment for leukaemia)

The potential causes of reduced activity and exercise include a reduction in both routine activities of daily living (such as walking, climbing stairs) and in more intensive exercise activities (such as going to the gym, playing sport). Physical deficits can present significant barriers to engaging in activity and may make young people more dependent on those around them for routine tasks. Prolonged hospital admissions, which may include enforced isolation due to immuno-compromise may provide little stimulus or opportunity to spend time out of bed and it may be physically difficult due to feeling generally unwell. Young people may be unable to engage in their usual everyday activities outside of treatment, such as work, education and social activities. Emotional barriers to activity and

TOP TIPS

for promoting exercise and activity

The reasons behind reduced activity are often multiple and complex, requiring a multi-faceted approach.

- Address any physical deficits which may act as barriers to activity and exercise
- Work with the wider multi-disciplinary team to identify and support TYAs with emotional barriers to activity.
- Provide advice and education on the importance of activity and exercise to young people and their wider support network as soon as possible during the cancer pathway. This advice should be adapted to individual circumstances and abilities.
- Create an inpatient environment which promotes activity and independence.
- Establish a timetable of organised activities and encourage young people to use different spaces on the ward instead of remaining in their room or treatment bay
- Investigate what exercise opportunities already exist in the young person’s locality (e.g. GP exercise referral, disability sport) to provide an exercise opportunity if this is not available through the hospital.

"I gained my health and energy back after long-term treatment"
(male, aged 19, following an exercise scheme after treatment for a brain tumour)

exercise may also be present, such as low mood, poor self-confidence and anxiety (discussed in other parts of this chapter). Young people and their families may feel anxious and fearful of causing harm by doing "too much" or the "wrong" thing, and believe that rest is best. In addition, it is part of normal development for TYA to need more sleep and to feel more tired than adults so poor activity levels may be an exacerbation of normal behaviour³⁰⁷.

Interventions to increase physical activity in young people during and after cancer treatment have resulted in increased quality of life, reduced fatigue, increased physical fitness and improved mood and confidence^{305, 308, 309}. Appropriately qualified Physiotherapists and

exercise professionals are well placed to deliver exercise programmes and advice what can help young people maintain an appropriate level of physical activity and prevent/minimise health complications. Dependent on the young person this could vary from facilitating usual activities of daily living to re-engaging them in high level exercise and sport.

FATIGUE

Young people with cancer experience significant and disabling fatigue both during and after treatment³⁰⁷ necessitating a multi-disciplinary approach including Physiotherapy, OT and other health professionals such as dietitians. Fatigue has been linked to distress and poor quality of life and is a barrier to engaging in normal activities^{301, 307}. Physical activity is recognised as the most effective way of managing adult cancer related fatigue and studies involving young people have also shown improvements^{307, 310}. Young people therefore need education and guidance around fatigue and how to introduce appropriate activity levels to avoid a cycle of increasing fatigue and reduced activity.

TOP TIPS

to help young people cope with fatigue

- Help young people recognise that fatigue negatively affects anyone's ability to function and can constrain independence for a period of time.
- Provide information and advice about strategies to manage fatigue and conserve energy.
- Help the young person understand the need to adjust to change, accept some dependency and that fatigue symptoms may be unpredictable.
- Help the young patient establish realistic expectations and personal goals.
- Utilise the opportunity provided by reduced energy levels to help the young person establish what is important to them and what their priorities are.
- Help young people adapt their lifestyle to meet changing energy levels; providing equipment and adapting the environment where necessary.
- Educate and advise young people on the importance of physical activity in managing their fatigue, and provide guidance and support in achieving an appropriate activity level.

PSYCHOSOCIAL WELL-BEING

THE PURSUIT OF 'NORMAL'

Young people suffering cancer face many unique psychosocial challenges, the illness and its treatment delaying or derailing normative social achievements. Research has indicated that although coping strategies vary from person to person depending on the stage of illness and the young person's pre-cancer lives, a prevailing goal for many young people was to achieve what they called 'normalcy'^{28,105}. For some, this meant 'picking up' where they had left off before diagnosis, while for others it involved the creation of a 'new normal'²³⁴. This pursuit of 'normal' is thought to be uniquely important to this age group of patients due to their developing sense of personal identity^{229,234}. For most young people it is therefore important to try and maintain as much normality as possible throughout their diagnosis and treatment to help sustain their coherent sense of identity.

PROMOTING PARTICIPATION IN LIFE

A number of members of the MDT can assist in this regard in particular the OT, Social Worker and Youth Support Co-ordinator. Encouragement to engage in normal activities such as work, education and social activities can help a young person retain a sense of normality throughout treatment. This in turn can reduce psychological difficulties such as anxiety or low mood, helping the young person gain a revised sense of achievement and purpose. It is important to talk to the young person about what is important to them, what they would like to be able to do, while ensuring personal goals are reasonably achievable within in a specified time frame.

TOP TIP

for promoting motivation

- Encourage the young person to design their own goals. This can help them identify progress and also enhances emotional well-being and maintains motivation. It is often helpful to involve parents/carers/family to provide encouragement.

OCCUPATIONAL THERAPY: ADJUSTING TO LIFE WITH AND BEYOND CANCER

OTs work closely with young people to assess the impact of their cancer diagnosis on their daily lives, helping to optimise independence so that they can do the things they want to while living with cancer. OTs also help support young people following completion of treatment exploring with the young

person what they would like to do in their everyday life as well as any longer-term ambitions and helping them to address barriers (whether physical or psychological). The role of the OT is to assist young people adjust to living with or beyond cancer by³¹:

- Helping the young person access meaningful occupations and activities;
- Reducing or managing physical symptoms (pain, fatigue, breathlessness);
- Reducing psychological symptoms (anxiety, low mood, low self-esteem, anger);
- Supporting the development of coping skills and promoting positive mental health;
- Increasing independence in tasks and activities;
- Improving or maintaining physical function;
- Improving quality of life.

“Occupational Therapy helped me to regain 'normality' at the end of treatment. After having so many setbacks she really helped by being there to talk to and looking at practical ways to get my life back on track.”
(24 year old male, Leukaemia)

“I struggled with lack of confidence at the end of my treatment. I found it impossible to hold conversations with people and avoided going out. This made me feel really down and also annoyed with myself because after what I'd been through having cancer I should be able to do anything. My Occupational Therapist helped me to think differently about myself and I was able to build my confidence back with her support.”
(22 year old male, 2 years remission for Lymphoma)

PROVIDING EQUIPMENT

Sometimes equipment is required to maximise independence and special consideration needs to be taken when addressing equipment provision for young people. Equipment may involve larger items such as bath-boards, toilet frames, shower stools, or wheelchairs to promote safety and

independence but the young person may be reluctant to accept equipment due to the way it looks. However, this can be overcome through sensitive discussion and negotiation. It is also important for the OT to assess the person in their home environment and liaise with appropriate community services such as social services if larger adaptations are required such as stair lifts, bathroom adaptations or re-housing if their current living situation is inappropriate for their needs, e.g. living in a flat with many stairs and no elevator if they use a wheelchair.

“I was having trouble bending to pick things up due to joint problems so the Occupational Therapist gave me some equipment to help me be more independent. I have been able to use the helping hand/grabber to get dressed myself but also use it to play with my nephew and niece and their toys. I can be involved in fun things now too and not feel like a boring auntie anymore!”

(22 year old female living with long-term side effects from stem cell transplant for Leukaemia)

There has been a gradual recognition that rehabilitation does not simply involve getting young people to function independently again. It means affirming people's lives no matter what stage of illness even toward end of life. OT continues to be important in helping young people toward the end of life to maintain as much independence as possible. Equipment may also help with comfort and safety at the end of life.

SOCIAL WELL-BEING

One of the most pressing challenges identified by young people is the perception that their social identities and existing relationships with peers, family and friends are altered following diagnosis²³¹. In addition to other members of the MDT, Social Workers and Youth Support Co-ordinators play useful roles in addressing these challenges.

FAMILY SUPPORT

Changing family relationships and compromised well-being

Young people with cancer have identified family relationships and in particular their mother as vital sources of support^{74, 243, 275}. The impact of a TYA cancer diagnosis is known to have a profound and long-lasting effect on the well-being of all family members as established relationships are thrown into crisis (Grinyer, 2008). Not unlike the ill young person, family members and in particular primary carers and parents experience overwhelming changes to life as previously known. They too report feeling powerless and must adapt to new roles and responsibilities, live with the uncertainty of an unknown future and increased financial concerns³¹².

Adolescence and young adulthood is known to be an important phase in the individual and family life cycle with particular challenges for both young people and parents alike^{103, 313}. With the onset of life-threatening illness, parents and young people are often thrown together in unexpected ways and spend more time together than they may have for many years. This can be challenging for both as they must negotiate the fluctuating dependence and independence associated with cancer treatment.

Young people can struggle with their normative developmental drive for autonomy while simultaneously

TOP TIPS

when discussing equipment

- Spend time explaining to the young person what the equipment is for and how it can help.
- Give examples of other young people who have found equipment helpful or ask them to talk to the young person about their positive experience of the equipment.
- Encourage them to try the equipment so they can experience the benefits.
- As much as possible, work with the young person to find equipment that is more pleasing to the eye. Items can be purchased privately that are more age-appropriate. In the UK the NHS has a wheelchair voucher scheme that gives patients the option of purchasing their own wheelchair (more stylish options) with an NHS contribution

desiring the safety and comfort of childhood, which is intensified when faced with life-threatening illness²²². They may wish to exert their independence at a time when parental dependence is mandated by the demands of illness²¹⁰. These contradictory impulses have been known to evoke feelings of frustration and lack of control. As well as a source of emotional support parents are known to play an important role with regard to the young person's medical needs, supporting treatment adherence, appointment attendance, information exchange and healthcare vigilance³¹². They too must get used to the layout, language and professional dynamics of a healthcare setting and find ways to establish their role in this highly professionalised environment³¹⁴.

While noting the importance of supportive healthcare professional relationships, parents also report struggling to find their place in the healthcare system, feeling at times unwelcome and on the periphery³¹². Negotiating and managing communication that prioritises the rights and needs of the individual young person while understanding the importance of family support raises complex challenges for healthcare professionals, young people and families alike²²². Coping with these multiple challenges is known to negatively impact family well-being, with some research indicating that the long-term negative impact on parental well-being may be greater than on the adolescent survivor²¹⁴. While NICE recognises the central role that families and carers play in supporting patient well-being it is acknowledged that their own needs often go unrecognised and professional support is not always available³¹⁵.

Social Work: supporting young person and family resilience

The Social Work role in TYA cancer care is multi-faceted addressing the emotional, practical and financial needs of each young person as well as supporting key carers and the wider family network to help manage these unforeseen challenges³¹⁶. While primarily hospital-based, Social Workers also visit young people and their families in their homes and communities liaising closely with teachers, schools, colleges and significant others. In the UK, these positions are often funded by the Local Health Authority or charities such as CLIC Sargent.

PEER SUPPORT

Young people living with cancer often report social isolation as they struggle to maintain friendship or initiate new relationships to maintain effective social support²²³. Peer contact with other young people living with cancer is recognised as an important source of emotional support and a critical component of 'age-appropriate care'^{16, 317, 318}.

Group activities: Promoting peer contact and relationships

Recognising the significance of peer support at this developmental life stage, which is often compromised by cancer and its treatments²³¹, peer groups can help young people share experiences, talk about concerns and have fun. In this way, young people are supported to regain some control over their lives. OTs, Youth Support Co-ordinators and other members of the MDT are trained in group work. This can be especially useful to encourage peer support.

TOP TIPS

for supporting family well-being and resilience

- Get to know the names of important family members. Help families feel welcome in the hospital environment.
- Family's lives are interconnected. Supporting family relationships will enhance the well-being of the young patient.
- Remember that family members will have their own struggles and needs that may require support. Refer to Social Work if you become aware of unmet family needs.
- Most families are doing their best in difficult circumstances. When conflict emerges between parents and young people, keep in mind the context of normal adolescent development and the abnormal experiences and challenges for all family members presented by TYA cancer.
- When faced with a dilemma, work closely with the young person and family members, always prioritise the best interests of the young patient but seek to understand the challenges for parents and find ways to support them also.
- The shock of a TYA cancer diagnosis and entrance to an acute healthcare system can elicit alienation, under-confidence and passivity in young people and their families. Healthcare professionals can help families navigate the system, providing explanation and orientation, enabling familiarity and predictability at a time of great uncertainty.

While more common in specialist TYA units, organising group activities or other social events, which encourage peer contact is possible and all the more important in non-specialist treatment centres where young people will not naturally meet other young people and families facing similar concerns. Groups can have a variety of purposes from psychosocial support, to educational and information giving, encouraging engagement in functional activities. The creative possibilities are endless.

Youth Support Co-ordinators: promoting youth development

The role of the Youth Support Co-ordinator within the MDT is unique to the UK. Funded by Teenage Cancer Trust these post holders tend to be based in Teenage Cancer Trust units. Their role primarily is to complement the work of the MDT by providing unique support services tailored to patients' needs as young people, rather than illness. They view patients as young people who happen to have cancer not cancer patients who happen to be young. They offer one-to-one support and organise age-appropriate group activities to keep young people active, engaged and connected with others, including their friends who have a cancer diagnosis and those who don't. The non-clinical role of the Youth Support Co-ordinator aims to create space and activities in an informal and relaxed atmosphere that facilitate opportunities for young people to foster resilience and continue to develop socially and emotionally.

Body Image Support Group

Some young people struggle with the changes to their body image induced by cancer treatment and the potential long-term side-effects. This can have a psychologically damaging effect on young people who just want to fit in and appear 'normal' to their peers¹⁶. A body image support group enables young people to meet other people going through a similar experience. This gives them the opportunity to talk about how changes to their body have made them feel and to learn tips for improving confidence. Conversations within the group cover a wide range of themes ranging from feelings around hair loss, weight changes, scars, skin changes, to loss of limbs and fertility. Following attendance at the Body Image Support Group facilitated by the OT at The Christie Hospital (Manchester, UK), young people reported improved confidence levels. They also stated that they had found it beneficial to talk to other young people and felt less alone with their feelings about body image changes.

Functional activity groups

Age-appropriate functional activity groups can also be facilitated such as baking groups, preparing meals and pizza groups. Young people who attend such groups indicate that it is beneficial to meet other patients who understand a little more about how they might be feeling and gain a great deal of peer support from these interactions. The groups also help address issues such as healthy eating and promote nutritional intake for patients who often dislike hospital supplied meals.

TOP TIPS

for TYA activities

- Engaging a young person in an individual or group activity can be a useful context to encourage dialogue, discussing thoughts and feelings in a relaxed environment. Activities can also help young people make new friends and get support from other young patients, reducing feelings of isolation and promoting normal peer contact.
- Make sure activities are meaningful and interesting for the young person, based on activities they enjoy, for example using cooking activities, games consoles or playing pool.
- Consider engaging young people's families as this can help strengthen important relationships and feel welcoming and inclusive.
- Start small and be creative. Build relationships with other members of the MDT or wider hospital staff who may be interested in becoming more involved and may have a particular interest, skill and original ideas that could be helpful.
- Think about involving charities such as CLIC Sargent, Teenage Cancer Trust or Northern Ireland Cancer Fund for Children as they may have expertise that you can utilise in your setting.
- It is helpful to regularly complete patient satisfaction audits to find out what young patients think of TYA services. Young people themselves may have very helpful suggestions for improving TYA services.

Group attendance also provides psychosocial and physical rehabilitation, where patients are actively encouraged to move away from their bed areas. Being occupied and distracted by activity can help to reduce anxiety and low mood.

Arts projects

Other possible TYA activities include arts and media projects, such as the JTV cancer support project, which allows young people to share their experiences of cancer creatively (<http://jtvancersupport.com>). One such project took place in the adult treatment centre of Belfast City Hospital where the TYA Social Worker and hospital Artist in Residence collaborated on an Arts project 'Moment by Moment', funded by local

charity. This project worked with young people and their families on the ward and in day-patient contexts using mediums such as screen printing and multi-media to talk about and depict their illness experiences in different ways or simply try a new activity. Project participants were supported to talk about difficult times, what had helped along the way, their hopes for the future, celebrate happy times and simply have fun. Healthcare professionals could also join in. Art pieces were then displayed on the ward and a DVD created. Such projects can provide a focus, helping young patients and family members talk about cancer in different ways, meeting other young people and families going through similar experiences. Such events can help young people and families break the silence, fear and isolation that often surrounds illness, make new relationships and find their voice and confidence in the unfamiliar hospital environment.

PROFESSIONAL WELL-BEING

THE IMPORTANCE OF SELF-CARE

One of the most important things professionals can do in their job is to look after themselves. Professionals are human too. It is highly likely that they will experience their own psychological distress and emotional reactions to some of the young people with whom they work. This might not just be sadness or hopelessness, but might also be feelings of frustration or anger. For example, it can be hard sometimes to be compassionate and empathetic to a young person who is very upset about something considered to be fairly minor in comparison to the difficulties of the young person they may have just seen before them.

SELF-CARE IN ENDINGS

It is important to acknowledge that members of the MDT may form close relationships with the young people they work with. They often also get to know their families and witness some of the emotions they experience along the cancer journey. While some young people will get better, some will not and some will sadly die.

Although close relationships may have been built with the young person, the professional may not get a chance to say goodbye or attend the funeral. Moreover, they may find out about their death in informal settings such as a corridor conversation on way to a clinic, which may cause distress. Since they worked with the young person in a professional capacity, the 'professionalisation' of the relationship can influence professional's beliefs about how much they 'should' grieve their death and what grieving in a healthcare role 'should' look like. Current literature encourages professionals to ignore the word 'should' in this instance and acknowledge their feelings. Smith & Martin³¹⁹ have written a useful chapter about mourning and grief in a professional context.

Reflective practice groups and team debriefs can be important for working with people who are dying. It is

important to remember that practitioners are human too and that they may experience distressing emotions in relation to some deaths. Practitioners are entitled to feel upset when a young person dies and this is not something that should be suppressed or criticised, even if the death was anticipated

TOP TIPS

in self-care

- Try to switch off when leaving work.
- Recognise the limits to what can sometimes be done.
- Talk to colleagues.
- Share clinical responsibility within the team.
- Use clinical supervision and reflective practice groups.
- Seek personal psychological support if needed.
- Remember to be kind to yourself and look after your own needs as well as those of others.
- Take regular breaks and use annual leave.
- *Looking after your own well-being will help you promote the well-being and resilience of the young patients you care for and their families.*